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ABSTRACT

Parents of handicapped children can provide valuable assistance to child caregivers and should be encouraged to become involved in the observation and education of their handicapped child. However, obstacles to optimal parent-caregiver cooperation may exist. Parents and caregivers may have different views of the infant and differ in knowledge of child growth and development; parents may be distressed by the birth of a handicapped child, and some parents may not immediately be able to respond to the emerging needs of the newborn and those of their spouse. Providers' attitudes may also reduce parent-caregiver cooperation if they reflect the disillusionment of caregivers, rigidity in use of materials, and disapproval of parents' lifestyle. Providers can improve communication with parents by (1) starting the relationship with parents as early as possible, (2) providing reliable support, (3) sharing knowledge about child development, (4) improving observation skills, (5) holding discussions with parents, (6) encouraging parents to think about the consequences of their behaviors, (7) encouraging parents to be positive, (8) sharing joy in small developmental advances, (9) praising specific achievements of parent and child, (10) treating the parent as an expert on details of the child's experiences, (11) using parent involvement techniques consistent with family needs, (12) marshaling community resources to serve parents, and (13) providing support for caregivers working with parents. (Author/RH)

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Working in Partnership with Parents of Handicapped Infants

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Three ideas about handicapped children have come to be challenged radically in the past decade. One was the notion that there was nothing much that could be done for educating a handicapped or retarded child before the school years. Current knowledge about the importance of building later skills on earlier infant learning is coupled with current sensitivity to early prevention of later potentially more severe disabilities. Such new understandings have led to efforts to begin work with infants as soon as possible after a disability or risk condition has been detected.

A second idea from the past was that handicapped youngsters always had to be in a special, protected, separate environment for their education. Today we know that while this may still be true for some children, others can best learn in a mainstreamed environment if there are proper supports and education of teachers, parents and classmates. The Brickners (1972) have successfully mainstreamed Down's syndrome preschoolers with normal toddlers in a program that counts heavily on parent participation for carrying out systematically prescribed learning exercises with the children.

A third idea was that only professionals could either diagnose or remediate handicapping or delayed developmental conditions. They were the experts. Sometimes professionals will reassure an anxious parent that a baby will "grow out of" a problem, or that the baby is "too young to tell" just yet if there is really something wrong. Often the first person to be troubled that development is not proceeding normally is the parent. The parent may feel strongly that coping with

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this baby is very difficult, that worries are frequent, that help is needed. Efforts to downgrade a parent's concern or dismiss a parent's fears can only lead to alienation of parents and lack of trust in professionals. Helping persons need to value parents as sources of special information about an infant's development. Valuing parents helps them counteract their own feelings of self-doubt at the crisis of birth of a handicapped infant. We need to respect the parent as a prime observer of infant characteristics that can give clues for appropriate remediation efforts. As Karnes (1979) has advised, "Think of parents as teaching resources who can contribute knowledge about and insight into their children, helping you to enhance educational programs." (p. 38).

Thus, the third notion has been replaced with realization that parents are the first and most loved and most available teachers of their infants. They are an important and crucial component in the front-line preventative and remedial work done with handicapped children.

Obstacles to Staff-Parent Partnership

Despite the new awareness and appreciation of the role of families as educators of their young handicapped children, cooperation between helping staff and parents may not be easily obtained. On occasion, staff desire to help the infants has not always been accompanied by sensitive enough efforts to build trust with parents, so that, for example, parents understood the reasons for certain stimulation exercises or curricular interventions urged by the staff. What are some of the aspects of parent involvement in optimizing the development of handicapped infants that can militate against a cooperative partnership between parent and practitioner?

Knowledge of Child Development

One of the difficulties that sometimes prevents communication between parent involvers and parents lie in the different views of the infant and differential knowledge about child growth and development that parents may have in contrast to professionals. De Lissovoy (1973) surveyed rural adolescent parents of infants to find out at what age most parents think babies can accomplish a variety of developmental tasks, such as sitting alone, social smiling, toilet training, saying first words, and being obedient to "no-no". Parental estimates in weeks of when children were able to complete developmental milestones or were able to recognize and be held responsible for behaviors considered wrong by the parent were totally out of line with developmental norms. Fathers, for example, believed that babies could sit alone at 6 weeks; the norm is 28 weeks for normally developing infants. Both parents believed that toilet training should be accomplished by 6 months, whereas neurological maturation that permits voluntary sphincter control may not be completed until after the second year for many toddlers. Most of the parents expected very little crying from their babies. During Dr. De Lissovoy's visits, he often witnessed excessive physical punishment of very young babies. Parents explained that the baby "had been asking for it all day" or that the slapped baby had already been told to stop crying and had disobeyed. Poverty, and very low tolerance for frustration seemed to increase parents' perception of infant caregiving as a very trying experience. Very few of the parents spontaneously cuddled or played with their children just for the "sheer joy of it" (p. 24).

Epstein (1978) has also found that teen-age mothers seem to be unaware of the developmental meaning of observed infant behaviors and parent-child interactions. Therefore, some parents may act unresponsive to the developmental needs of their babies for supportive stimulation, verbalizations, and responsive interactions. Thus, a thorough knowledge of normal and delayed infant development stages and

processes can help a provider help parents. Parents have a basic civic right to child development knowledge (Honig, 1979).

Grief and Anger

Most parents are prepared for the birth of a normally endowed, perhaps even an ideally endowed baby. The birth of a handicapped infant or an infant at risk poses a massive threat to the parent's inner picture of a "good parent". Feelings of denial of the reality of the handicapping condition may arise. All is well. Nothing is really wrong with their baby. They resent the professional who is suggesting terrible, threatening ideas of defect or danger. They may ignore professional advice and suggestions.

Feelings of rage and of grief often mix together and flood a parent with emotional distress. Numb, unreal feelings about the actual existence of the handicapped baby and wishes that the baby might die may arise. The hurt feeling that a particular baby will never grow up to be the son or daughter dreamed about may interfere with early ability to focus on the real baby whose needs for special care may be so urgent. Emotions of panic and irritability may be augmented by physical exhaustion if a parent is caring for a baby who has difficulties with breathing, feeding or sleeping.

Neediness and Anxiety

Insecure and depressive feelings may accompany even normal pregnancy and delivery. Usually, hopeful and positive feelings surge up as the newborn is held and beheld by the parent. Loss of the dream of a normal baby is a real deprivation. Like other deprivations, such as financial struggle or abandonment by a loved partner, deprivation of the normal baby that the parents expected can lead to hopelessness or resentment about ability to fulfill the parenting role. Since the handi-

capped neonate was so much a part of the mother's body, the newborn can come to stand for "bad" unwanted parts of the mother, just as aspects of the new baby can revive happier, more cherished aspects of the mother's self. Kaplan (1978) suggests that even before birth "the baby-to-be has been an angel and a monster" (p. 66). The birth of handicapped neonates may precipitate feelings of self-hate and of maternal alienation from the "monster" aspect of the baby that the handicap represents. When the baby has been born to a mother who has herself been poorly parented in the past, the guilt at having produced a "bad" baby literally, coupled with having been the "bad baby" psychologically in her own family may awaken ancient angers and hatreds, toward the self and toward the new baby.

Sometimes a series of deprivations coincide, as when an unwed, young mother bears a handicapped infant. Professionals need to be deeply aware of the ambivalent feelings and especially of insecure feelings about mothering ability that may ensue. Such a mother may have hostile feelings toward the baby and also great anxiety about whether the baby "loves" her. The author was once present in a therapeutic day care center for at-risk infants. A teen-age mother thrust her baby suddenly into the arms of another young mother. The baby screamed. The mother smiled triumphantly, snatched back her baby and repeated the thrusting away of baby to another person's arms. Again the infant cried out terrified. Turning to the author, the young mother said defiantly "See, that proves she loves me best and I'm a good mother, 'cause she cries when she's in <u>their</u> arms!" Kaplan has noted that in some mothers, deprivations can lead to "awakening of the unloved self" (p. 65) possibly followed by anxiety, depression and panic.

Further, some parents, particularly fathers, may be "so out of touch with memories of neediness that they find it impossible to empathize with neediness in others. They resent being needed and resent those who are in need" (Kaplan, 1978, 67-68). Since newborns with handicaps often need special care and attention for

long periods after birth, parents may come to see their babies as being totally needy and dependent on them. This can awaken old anxieties about dependence and neediness. An important antidote may be to allow fathers to participate in the birth process and in holding the newborn so that emotional openness to nurture and empathize with the baby can be enhanced.

Attachment Status and Early Learning

During the past decade, intensive research on securely attached versus insecurely attached infants has revealed the critical importance of the attachment bond as an organizing force which permits the infant to learn. Sroufe (1981) and his colleague have found that when year-old babies were securely attached, then, later as toddlers, they were able to persist longer at tool-using tasks, in comparison to toddlers who had been insecurely attached earlier. The securely-attached tots were more prone to enlist the parent as helper when the problem-solving tasks were quite difficult, and they exhibited far fewer tantrums than insecure infants in the face of frustration.

Ainsworth and her colleagues (Bell & Ainsworth, 1972) have demonstrated that securely attached infants can be more easily comforted by caregivers. Such infants can also use the parent as a "homebase" from which to go forth and explore toys and environment. The importance of this enablement lies in the fact that it is "the (baby's) active, coordinated alert engagement with the environment which sets in motion early learning (Escalona, 1980). Thus, the parent as the primary infant caregiver, has come to assume new importance as a force for learning in the life of the handicapped infant. Handicapped infants who are well-attached to their parents will be more able to utilize environmental encounters as grist for early learnings. Professionals need to nurture and encourage bonding and attachment of program infants and parents. They will be promoting the growth of a positive affective matrix out of which can grow intellective motivations and strivings for perceptual-motoric competence. Some program personnel overemphasize lessons and exercises and do little to nurture the emotional relationship between parent and

child which supports learning.

Secure attachment is also important because of its relation to compliance. Research on securely attached infants has revealed how closely attachment and cooperation with parental demands are related (Stayton, Hogan and Ainsworth, 1971). Mothers who used warmer voices in giving commands and gentler physical handling at 12 months had infants who at 21 months were more compliant and cooperative not only with their mothers but with an adult woman playmate and with an infant test examiner (Londerville & Main, 1981). Handicapped infants will often have to struggle harder to accomplish developmental tasks. Frustration may be sharper than for normal babies. Certain handicapping conditions may require persistent efforts at therapeutic exercises or even at simple self-care tasks. Professional encouragement and support for maternal-infant emotional closeness may well prove to enhance the cooperation of toddlers with prescriptive procedures that must be carried out as part of remediation efforts.

Provider Attitudes that May Interfere with Effective Partnership

Disillusionment.

Sometimes providers of services to handicapped children begin their efforts with a missionary zeal. They may feel frustrated and indignant that parents do not carry out all the prescriptives delivered with such good will. They may not be sensitive enough to parent resentment that the professional seems to be "taking over" the baby while demonstrating or giving suggestions about work to be done. Also, if the infant is developmentally very slow in making progress, some of the provider's zeal may evaporate. The provider may secretly believe that the parent is not cooperating well enough between home visits by carrying out requested pro-

cedures. Disillusionment may lead a provider to "give up" on a parent as not caring or trying hard enough. More patience and awareness of realistic expectations for growth processes may help bring worker and parent into a less adversarial and more cooperative effort.

Rigidity

Some trainers in work with handicapped persons perceive that they must use special materials or procedures in certain ways only. Rigid use of training materials without sensitivity to the home circumstances, to parent feelings, or to infant level of ability or interest may lead to discouraged feelings on the part of a provider. Honig (1981) has suggested the concept of "dancing the developmental ladder". Tasks and games and processes of interaction should be so tailored that the small child is lured forward to try tasks just a tiny bit more difficult or more novel. Conversely the task may be made less demanding so that the baby can be emboldened to try. Flexibility in making task presentations or requirements more difficult or easier so that babies are helped to engage in efforts is preferable to rote presentation of prescribed items where the baby is not actively engaged in the learning interaction.

Value Conflicts

Some professionals disapprove of the life-style of parents and allow this feeling to color their perceptions of the parent-infant relationship. Parents can be positively encouraged into loving facilitative interactions with infants in circumstances that may be messy, dirty or even "immoral" to the worker. What is important is the process of the intimate relation between parent and child. One worker reported with shock that she found the baby sleeping on the floor on a blanket in a cold empty room when she came to carry out the home visit. The baby

was in no physical danger, nor was she otherwise neglected. Poverty of furnishings is not necessarily coupled with poverty of caring. Of course, if there are physical dangers or poor nutritional practices, then child development information can be communicated in a manner that conveys how much the parent and the worker both care for and about the welfare of this baby.

Suggestions for Building and Maintaining Parent-Professional Partnership

Given the difficulties of emotional adjustment that so many parents of handicapped infants undergo before the processes of reconciliation and getting on with the work of loving and rearing can come into play, what can a service provider do to improve communications with parents and the partnership process?

1. Start a relationship as early as possible post-partum with the parent(s).

Parents right after birth need support and are likely to be more willing to be recruited into a program that offers support. Neonatal enrichment efforts may have the biggest payoff in terms of commitment to program and growth together in the difficult enterprise of helping the at-risk infant develop optimally.

2. Meet the parent's needs whenever possible for a reliable support system.

Building trust takes time and often involves a "show me" attitude on the part of parents. Such a trusting relationship can serve to buffer the parent against frustrations and angers with institutions and systems that do not seem to be responsive to his or her needs or the needs of the handicapped baby. For example, last year, a visiting nurse reported that as the months after birth went by, during which she continued visiting a mother, the doctors kept demanding that the baby be brought in for more and more tests and procedures. Gradually toward the end of the year, medical staff suggested that the baby might indeed not only be develop-

mentally delayed but also deaf and possibly blind. The mother felt crushed. She felt that the truth had been kept from her. She had not been advised at each point about what was suspected or being tested. She had been given no inkling after birth of the possibly massive nature of the deficits now being mentioned. The parent poured out her anxiety and despair during visits and on telephone calls. The professional listened emphathetically. Grief can be even more overwhelming when there is nobody who seems to care. Bromwich (1981), in her program for at-risk infants gives primary emphasis to empathetic listening:

> "our approach to intervention required that we first listen to the parent carefully, that we acknowledge her feelings, that we be empathic with her by trying to see things from her perspective, and that we try to understand her perceptions of her child and of herself as parent... While we listened empathetically, we communicated to the parent that we valued hearing her talk about what was preoccupying her and that we tried to hear what she had to say in a non-judgemental manner, i.e. that we accepted her regardless of the feelings she might express. We helped her realize that most parents feel frustrated, ambivalent or angry. Our acceptance and the parents' realization of the universality of their feelings often provided them considerable relief. (p. 175)

3. Share knowledge about normal and delayed child development.

Parents depend on providers to bring a professional understanding about infants. Sometimes what looks like inappropriate deliberate mismanagements on mother's part results from lack of understanding of infant comfort, anatomy, or activity. A mother in the pediatric waiting room was trying to dress her infant who had a cold and a stuffy nose. Mother lay the baby with head dangling down on her lap. He fretted and cried as mucus clogged his breathing. The mother, to quiet him, popped a pacifier into baby's mouth. The baby's struggles grew wilder and more frantic. A parent worker came over andasked permission of the mother to help in dressing the baby. The mother with relief watched as the worker held the baby so that his head was above body level. The child quieted and was able to be dressed. The worker matter-of-factly explained how babies breathe and how scared they feel when they

can't seem to breathe well. Simple calm explanations increase parent competence rather than leave a parent feeling inadequate or incompetent with her baby.

4. Build your own and the parent's observation skills.

Child-watching is an art and a skill. The more we can learn to watch a child with the parent and be able to point out tiny advances or changes in behavior, the more we can help a parent to become a better observer of his or her own baby. Bromwich (1981) has reflected that

> "the kinds of comments that accompanied our observations of the child's play, language, affective cues, social responses, and motor behavior called the parent's attention to the details of behavior that revealed important developmental changes in the child, no matter how small. Observing with the parent meant that parent and staff shared with each other what each had observed. The discussions that ensued from the observations were motivating to the parent to continue to observe, and they gave her additional ideas about what was important to look for in order to help her interact more pleasurably and effectively with her child. Observations and the accompanying discussions also made the parents more interested in investing more time and energy in providing the kinds of play opportunities that the child seemed ready for." (pp. 176-177).

Observation skills can be brought into play to encourage staff and parents when progress seems discouragingly slow with a severely handicapped infant. A parent, for example, can notice that the baby's hand is no longer so tightly clenched, but that the fist sometimes opens now in response to stimulation.

In a hospital room, a mother reported feeling upset about trying to bottle-feed her newborn. The carefully observant parent worker noticed that mother held baby's head so that the cheek opposite to the mother's body was stroked. In response to the rooting reflex, the infant naturally turned his head away from mother. When mother was helped to notice this and to understand the rooting reflex, she was better able to feed her baby without feeling rejected.

Observation skills can attenuate staff burnout. If a profoundly retarded toddler is only able to perform, for example, at a Piagetian stage 3 sensorimotor

level, then limited activities can be introduced. Nevertheless, the observant worker, using Piaget's principle of "horizontal decalage", will use different materials or modes of arousal to elicit any behavior of which the infant is capable. These skills can be taught to parents. If a baby can visually track a flashlight beam 180 degrees, can she now also learn to track daddy's keys that jangle, or a pop-it bead necklace slowly moved across her field of vision?

5. Discuss child behaviors and interactions with parents.

It may be difficult at times to know when professional observation should be used to begin discussion with a parent about inappropriate adult behavior or missed opportunities for enhancing the infant's responses. If professionals show off their skills too much, they may make parents feel inadequate. If they consistently ignore inappropriate behaviors of parents, this may be inimical to the infant's best interests. Choices are not always easy. A mother had brought her poorly thriving baby into the clinic for evaluation. Mother sat in a chair quite near the high chair where testing toys and items were being presented to the infant. At one point the infant threw a toy from the table and started to lift himself upward a bit in order to peer over the edge of the table to recover the toy with his eyes. "No-no!", the mother said, very sharply. Baby looked scared and started to cry. This was a good time to explain easily about what "no-no" means to a 9-month old infant. How can a baby figure out precisely what is forbidden or bad? If he reaches toward something hot and we say "no-no" and take the hand away and say "hot!" in a serious tone, then the baby may learn in that interaction what "no-no" means. If too often we use generalized sharp warning prohibitions, then the baby may simply come to feel that she is the "no-no"--the bad creature. This mother had been afraid perhaps that the infant could lift himself out of the high chair into which he had been securely strapped. We need to reserve sharp negatives for serious situations where babies can better understand our meaning.

Helping a parent to see the situation from the viewpoint of the baby can promote increased sensitivity to infant needs and infant levels of understanding. For example, if a parent is dragging a screaming two-year old down the hallway of a respite care center, a worker might comment, "It sure is tough to try to walk as fast as a grown-up when you have little legs. It makes you feel all upset to try to walk so fast when a person is so little!" Some parents simply have not learned how to look at the world from a tiny person's point o view, especially a tiny person with handicaps. Warning: Some parents are so needy themselves that this method may simply call forth the rejoinder, "He can so do it. He's just trying to irritate me today!"

In discussion times, professionals may get more attention and interest if parents initiate topics. Behaviors that the parent perceives as worrisome or aggravating often provide good opportunities for staff to introduce new ways to think about infant behaviors, new ideas about why tots carry out actions that adults might find messy or naughty. Most parents have little idea of the deep need of toddlers to be active, to roam, to explore, to search for, to take apart, to pour in and out. Helping parents see the meanings of behaviors for the child can sometimes lessen the parent's anger at what is considered deliberate defiance. Such a view of the developing child may lead to discussions of more appropriate ways to protect family possessions from toddler curiosity. Staff can support parents' search for ways to promote toddler exploration through activities the parent may choose as more acceptable than "messing" with food, for example.

Dialogues with parents slowly build new ways of seeing what a tiny person is like. Dialogues with parents slowly give parents an opportunity to feel free to try alternatives to some of the unthinking punitive ways some adults use in dealing with "naughtiness" in small children.

Encourage parents to try alternative ways to solve their problems with their children. Research has shown that the more alternative solutions children and adults can generate to solve their own interpersonal problems, the more successful they will be in their encounters with problems (Shure & Spivack, 1978).

6. Encourage parents to think about the consequences of their behaviors.

Sometimes in discussions, new ideas or behaviors are introduced, but there may be little parent follow-through. Encourage parents to take the "What will happen if...." attitude. If we read daily and engage happily in language activities with a speech-delayed child, then vocalizations and increased interest in language may result. If a parent habitually presents a hemiplegic baby with a toy in the hand that does not function rather than the hand that can function, what is likely to happen to the goal of encouraging infant advances in reaching for and obtaining toys?

7. Encourage parents to accentuate the positive.

Many parents of handicapped youngsters become preoccupied with what the infant cannot do. Staff needs to help the parent find ways to encourage what the infant can do. For example, a blind five-month old cannot see the visual mobile over her crib. In order to encourage infants' circular reactions of kicking the mobile, getting a pleasurable feedback from their own actions and then resetting this process in motion, parents of blind infants can be encouraged to use mobiles that produce noise or music on being set into motion. The infant can respond to auditory feedback with the same delight that a sighted baby brings to her experiences in playing with gaily swinging toys (Bower, 1977).

Sometimes parents of handicapped youngsters act overprotective. They worry about falls and dangers. Instead of yelling "Don't run, you'll get hurt", a parent can be encouraged to call out "Walk slowly, Johnny", or, "Swing gently". Parents

may find it a relief to be able to state what they do want rather than what they don't want from their children.

Sometimes parents of slow-learning children feel upset and threatened by the child's slowness. They may feel a need to push their little ones into giving rote responses. In one program for disadvantaged small children, the mother's "usual pattern was to present a difficult problem and then to punish error or silence with nagging threats. They told the child to sit up, to pay attention; they informed him that they knew he knew the answer, so he better say it" (Risley, 1970, p. 145). Mothers in this behavior-modification program were taught how to recognize child behaviors that could be praised and how to use positive reinforcement to give their children attention and praise for behaviors that they wanted the children to continue.

8. Share your joy at small developmental advances made by infants.

Telling parents what we see as professionals may not be as useful as helping parents to "see" the child with new eyes. The author was working during a second visit with an iron-deficient, solemn-faced infant who lagged developmentally. As the baby picked up two blocks and tentatively brought them toward the midline, I remarked, sharing my delight with the mother: "You remember last week that Leroy could only use one block at a time. Today he is picking up two blocks and even trying to move them toward each other a bit! He isn't able to patty-cake with the blocks yet, but just see how hard he is trying to get those blocks together. He is working so hard. It is so exciting to watch a baby trying!" The mother looked radiant. She said that she did remember that the baby could not use more than one block to "go bang-bang" on the testing table the week before. She became excited at her own ability to observe and appreciate small steps forward. The tester's delight with the baby came across also as a delight in the mother of such a child

who could learn, who could try. The mother later volunteered noticings of her own that she had begun to tune into after the first assessment session with the baby the week before. Assessment sessions provide a fine opportunity to build a mother's pride in her observation skills and appreciation for her baby's early learnings.

9. Praise specific achievements of both parent and child.

While demonstrating a new task, the skilled professional often asks a parent to try the game or to model the task for the baby. This gives the parent a chance to practice a skill and to be in the position of "expert". It also gives the worker a chance to praise a parent warmly for specific work or for perceptive and positive ways of interacting with the child. Be sure to use specific praise, such as: "Bobby really stretches his hand up to reach when it is you, his very own papa, who is getting him to reach just a bit more with those little hands."

"Lianne comforts so nicely when you pick her up and cuddle her if she needs some hugging. You are so good at comforting her."

"He really listens when you are trying to talk with him. Mama is an important person to listen to. Babies love to hear mothers talk with them."

10. Treat the parent as expert about details of the child's experiences.

Ask questions to build a parent's observation skills. Using the parent as informant will enhance self-esteem. "What kinds of sounds have you heard Andrea making? Have you heard her try to put a vowel and a consonant together yet..as in buh-buh? What kinds of things seem to set off Daryl's tremors and stiffening of the arms? What do you try when that happens?"

11. Use a variety of parent involvement techniques depending on family needs.

No one way to reach parents succeeds with all families. A variety of program models are available for parent involvers to choose from (Honig, 1980). Some pro-

grams mix and match methods to serve parents better. They may carry out home visits. Yet, in addition, parents and toddlers may be bussed to a center several days a week so that special group activities can occur (Jew, 1974). Trained teachers can serve as expert models for parents during these sessions. Also parents get a chance to meet with one another.

Some programs add a weekend half-day session for fathers. Some programs mix practical guidance in child management with therapeutic counseling for parents still struggling with distress and difficulty in recognizing and accepting the child's problems. Parents actively involved in therapeutic techniques with their own infant often gain more acceptance of the handicap and more assurance in the role of parent, teacher and therapist.

Special program "extras" may make all the difference. Some programs have a "retreat house" where fathers, mothers and children can spend a weekend. Family get-togethers, sports and child-development discussions in a homey, friendly atmosphere give program goals a boost. Some programs have a psychiatric 24-hour "hot line" service for parents in crisis. Provision of a variety of extra services may increase the motivation of some parents to become more actively involved.

Parent-to-parent models have been particularly successful in helping parents cope with some of the agonizing personal problems that may arise after the birth of a handicapped infant. How shall relatives be told? Many such problems can best be helped by enlisting the support of parents who have already coped with having a developmentally disabled newborn in order to help those who are first facing the problems (Bassin & Drovetta, 1976). Training parents as providers for other parents may be an important and helpful aspect of your parent involvement program.

Not only may different modalities of service provision be used, but priorities may need to be set concerning the level of involvement that can be expected of a particular parent. It may be of little impact to hold an enthusiastic session on

making mobiles for a crib with a mother who avoids eye contact with her infant and is reluctant to handle or cuddle him. Bromwich (1981) suggests that parents can be helped to progress from lower levels of involvement to active, self-initiated participation in enriching activities with their infants. The "Parent Behavior Progression" devised by Bromwich provides examples of parent behaviors that reflect increasing involvement from level I to VI.

Level I: The parent enjoys her infant.

Level II: The parent is a sensitive observer of her infant, reads his behavioral cues accurately, and is responsive to them.

Level III: The parent engages in a quality of interaction with her infant that is mutually satisfying and that provides opportunity for the development of attachment.

Level IV: The parent demonstrates an awareness of materials, activities, and experiences suitable for her infant's current stage of development.

Level V: The parent initiates new play activities and experiences based on principles that she has internalized from her own experiences, or on the same principles as activities suggested to or modeled for her.

Level VI: The parent independently generates a wide range of developmentally appropriate activities and experiences, interesting to the infant, in familiar and in new situations, and at new levels of the infant's development.

It could be very discouraging for a worker who expects a mother not yet successful at Level I to participate in program efforts that demand Level VI skills and engagement. The partnership between worker and parent must be sensitive to the "match" or "mismatch" between the level at which a parent is functioning in her or his role and the program expectations of where the parent "should" be functioning. Partnership will work best if the level at which the parent is functioning is nurtured and appropriate activities and trusting interactions are engaged in so that the parent can progress slowly toward the next higher level of functioning.

12. Marshal community resources to serve parents.

Provide a respite center for parents of handicapped young children. One of the best ways to get parents to cooperate with program goals is to cooperate with parent needs and goals. Most parents with severely disabled small children need some form of respite care so that they can attend to their own personal needs as human beings. Erikson long ago taught us that the young child can grow up to be a giving person if he or she has been generously given unto during infancy and the early years. Parents need the giving acceptance and encouragement of staff in order to feel ready to give of their efforts to carry out staff suggestions. Provide a free subscription to the magazine "The Exceptional Parent", which is filled with good ideas for practical guidance for parents of handicapped youngsters of all ages.

A literature and audiovisual library may help parents feel free to browse among materials to learn and understand more not only about the particular handicapping condition of their infant, but about infant development in all children. Parent's Magazine and others have produced useful film strip series on parenting handicapped children. Subscriptions to publications of the 'Council for Exceptional Children' and the 'National Center for Clinical Infant Programs' will be useful. Parents as well need access to materials on quality infant caregiving and how to nurture growth and development. (For example, see: Honig & Lally, Infant Caregiving: A Design for Training, 1981.)

Research materials may be of interest to some parents. For example, Carew (1980), in her research report, reveals that regardless of whether infants were home-reared or day-care reared, the intellectual experience that most powerfully predicted IQ and intellective competence by 3 years of age was the situation where an interactive caregiver taught the toddler new words and created language-mastery experiences for the little one.

13. Provide supports for parent involvers

Workers who face daily the difficult problems of families in crisis after the birth of a handicapped infant need support systems too. Reaching out to parents and encouraging them to become loving, effective teachers of their infants requires extraordinary commitment, stamina (particularly for home visitors in snowy cities with infrequent bus service), tolerance, flexibility, and patience as personal skills. Additionally, the worker needs people-helping skills to work with adults in crisis and needs child-development knowledge, particularly focussed on the tasks and gains of the sensorimotor and early preoperational period.

A supportive supervisor is a boon to parent involvement personnel. They can express their worries, concerns, ask for counsel, turn to the supervisor for community resources and literature suggestions when a family's needs require additional aids. When a supervisor meets regularly with family workers, these problems and possible ways to handle them can be shared in the group. Staff training that provides rich opportunities for mutual feedback can help workers weather some of the storms of families in crisis.

Conclusion

None of us can help all people all of the time. But much can be done to increase the chances of families for supporting the growth and development of their handicapped infants and toddlers. Such efforts require personal skills and professional knowledge that may encompass several disciplines. Effective parent involvers need to be learners--forever increasing their areas of competence which, in turn, may increase their effectiveness with families. A parent involver needs to be able to coordinate services, to move from one intervention model (such as home visitation) to another (group meetings) as family needs and strengths dictate. A parent involver needs to be an advocate for the family and for the child. Concern for the

needs of adults and children will require sensitive efforts to encourage adult development and yet remain alert to the needs of infants. A well-functioning program will nurture the needs of workers for support and for extra knowledge in order to increase the effectiveness of staff for helping parents nourish the development of their handicapped babies.

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